



Assisted Decision-Making (Capacity) Bill 2013 Comments from of the College of Psychiatrists of Ireland

1. Introduction

- 1.1 The College of Psychiatrists of Ireland welcomes the publication of the Assisted Decision-Making (Capacity) Bill 2013. This is an exciting and progressive initiative which offers real hope for the empowerment of thousands of individuals who require assistance making certain decisions at certain times.
- 1.2 When the legislation is finalised it will replace Ireland's current ward of court system which is extremely outdated and problematic in terms of human rights. The current wardship system has an all-or-nothing approach to capacity; does not adequately define capacity or lack of capacity; is poorly responsive to change; makes unwieldy provision for appointing decision-makers; and has insufficient provision for automatic periodic review.
- 1.3 Overall, the Bill introduces three major conceptual changes to Irish capacity law:
 - First, the definition removes the requirement for there to be any impairment or disability affecting capacity.
 - Second, the Bill moves Ireland from a "status-based" approach to capacity to a "functional" approach. This means that an individual with, for example, moderate intellectual disability, would no longer be presumed to lack capacity simply because he or she has a disability. Instead, that individual would be presumed to have capacity and, if that capacity is called into question, capacity is to be determined in a decision-specific, time-specific fashion; i.e. for any given decision, capacity is to be decided based on the individuals understanding of *that* decision, at *that* time. And while an individual may have reduced capacity for a certain decision today, he or she may well have capacity for other decisions today, and may regain capacity for all decisions in the future.
 - The third major change is that this Bill places strong emphasis on the "will and preferences" of the individual. This increased recognition of "will and preferences" is both welcome and important.



1.4 The College is also pleased to welcome the following features of the Bill:

- Guiding principles that include minimising restriction and emphasising the person's own will and preferences
- The establishment of a number of options for individuals whose capacity is or may soon be impaired, including such as assisted decision-making, co-decision making, interim orders in emergency situations, decision-making representatives and a new system of enduring power of attorney (EPOA);
- The inclusion of healthcare decisions in this paradigm;
- The provision for periodic review of declarations regarding capacity by the Circuit Court;
- Plans to review the cases of all current wards of court in accordance with the new system before the third anniversary of commencement, and the fact that such individuals can be discharged from wardship or have ancillary orders made as appropriate to their needs;
- Establishment of the Office of the Public Guardian.

2. General Comments

2.1 In the first instance, the Bill as a whole appears to be primarily focussed on persons who currently have or once had capacity. It is unclear how persons who have always lacked capacity and are currently not Wards of Court will be afforded the protections of this Bill. The College believes it is vital that all people with impaired capacity are guaranteed access to the processes laid out in the Bill.

2.2 One of the drives behind this legislation has been the need to address the lack of legal capacity attributed to current wards of court. Unfortunately this deficit is not addressed in this Bill. The College is of the view that it would be most desirable if individuals who lack mental capacity could exercise legal capacity in *all* areas, including those areas exempted from this legislation (e.g. marriage). Section 106 of the Bill lists a range of areas (e.g. marriage) which are not affected by the Bill and for which, therefore, existing laws are unchanged. The exemptions from this legislation present complex dilemmas (see Section 8.1, below).



- 2.3 The interface between the Bill and the Mental Health Act 2001 needs to be clarified. For example, it is not clear if an individual who has a co-decision-maker or decision-making representative can be considered a voluntary patient in an approved centre (i.e. an inpatient psychiatric facility approved under the Mental Health Act 2001).
- 2.4 The College would also welcome clarification about advance directives in relation to healthcare; this will hopefully be introduced into the Bill at a later stage.

3. Specific Comments on the Bill's Guiding Principles

- 3.1 The College welcomes the Bill's presumption of decision-making capacity and specification that all interventions in relation to decision-making assistance must minimise restrictions of rights and freedom of action, and have due regard for dignity, bodily integrity, privacy and autonomy. There are important, empowering principles.
- 3.2 The Bill does not, however, resolve the issue of persons who lack capacity and are admitted to healthcare facilities on an apparently voluntary basis (i.e. the "Bournewood gap") (e.g. persons with dementia who lack capacity and are in nursing homes; people with intellectual disability who lack capacity and are living in a supported home). In addition, this Bill appears to suggest that admission to residential facilities may occur as a result of a decision making representative or EPOA. Such admission may not be in keeping with the individual's will and preferences, and may thus constitute abuse. This needs to be addressed and monitored closely.
- 3.3 The College welcomes the Bill's emphasizes the "will and preferences" of the individual. There is still, however, an important role for the principle of "best interests" and this principle should be restored to the Bill. The concepts of "will and preferences" and "best interests" are by no means inimical to each other and, once applied in the context of the other principles of this Bill and within a broader human rights framework, both concepts have roles in addressing the complex situations which occur from time to time among individuals with fluctuating capacity.

The Mental Capacity Act 2005 in England and Wales places "best interests" at the heart of its legislation, stating emphatically that "an act done, or decision made, under this Act



for or on behalf of a person who lacks capacity must be done, or made, in his best interests” (section 1, principle 5). The relevant code of practice in England and Wales presents a “best interests checklist” which also incorporates the importance of the person’s own views. This has *not* proven a barrier to the UK both signing and ratifying the United Nations’ Convention on the Rights of Persons with Disabilities. In fact, the inclusion of the principle of “best interests” in legislation greatly strengthens protections of human rights for individuals with impaired capacity, and strongly promotes their dignity and welfare.

Unfortunately, Ireland’s new Bill, as presently written, misses an opportunity to articulate a realistic, principle-based balance between autonomy and care and support that are in the individual’s “best interests”. While the Bill’s emphasis on “dignity” may go some way toward addressing this dilemma, reintroducing the concept of “best interests”, combined with “will and preferences” and the other principles in the Bill, would provide much-needed clarity for hard-pressed families and carers.

Including “best interests” would provide an important safeguard for individuals with impaired capacity whose will and preferences cannot be determined (e.g. some individuals with severe intellectual disability). Most importantly, it would promote more dignified, empowered lives for individuals whose capacity may be in question, and help realise more fully the aims of this important, progressive Bill.

- 3.4 The College recommends that the Bill include the ethical principle of reciprocity by which it is right and just to treat a person with mental illness who lacks capacity in order to restore them to health and capacity (and so restore autonomy).

4. Informal Decision-Making

- 4.1 This section of the Bill provides cause for significant concern.

Many persons currently in Ireland’s intellectual disability services lack capacity to significant degrees in relation to certain matters, and, in the most severe cases, some lack it in relation to virtually all matters. Their welfare is *not* protected by this Bill. The College had hoped that the Bill would deal with the concerns practitioners currently have in carrying out their daily work with such persons; e.g. prescribing medications, implementing behavioural interventions, designing person-centred environmental



changes, and engaging in restrictive practices when indicated in the persons' best interests (e.g. restraint, seclusion).

For example, persons with intellectual disability and other illnesses occasionally need phlebotomy (blood tests) and other painful interventions which they may resist (e.g. vaccination). Restraint is sometimes used in such circumstances in order to carry out the procedure in the best interests of the person. It is the view of the College that this Bill's provisions regarding informal decision-making are insufficient in view of the intrusiveness and coercive nature of such necessary actions.

- 4.2 Even more concerning, if the safety or life of an individual with intellectual disability is at risk because of absconding from the place where he or she lives or works, this Bill does not appear to provide any legal basis for preventing the individual from leaving. This is likely to be a key issue with families of individuals with disabilities, who regard intellectual disability placements or residences as places of safety for their family member. This may no longer be the case under the new Bill.

While the new Bill seems to provide indemnity to practitioners in at least some of these circumstances, it does not offer equivalent protection for patients, or guidance and support for practitioners who want to ensure that they are making appropriate decisions in line with the principles of the legislation which, as presently written, do not include the "best interests" of the person. The College realises that the Informal Decision-Making section of the Bill is meant to facilitate necessary interventions with people who lack capacity, but there needs to be greater oversight in order to protect patients lacking capacity and to give guidance to clinicians in their dealings with them.

- 4.3 As a result, there is a need for rules or practice guidelines setting out the limits to informal decision-making and indicating when a higher level of decision-making support (e.g. co-decision-making or decision-making representative) is more appropriate. This is likely to be a significant issue with families, especially those with elderly family members who wander at night or family members with intellectual disability who abscond, necessitating that families lock their front door. This Bill, as presently written, offers no solution to this common dilemma and no guidance to hard-pressed families who struggle with these issues daily. Nursing home managers and directors of residential services for people with intellectual disability face a similar dilemma, unresolved by the Bill.



4.4 Some, but not all, of these issues may be addressed through a Code of Practice for Informal Decision-Making, prepared by the Office of the Public Guardian. There will need to be careful consultation with all the relevant stakeholders and bodies when developing such a Code of Practice. Even then, however, there will still be an important unresolved issue in relation to oversight, especially in relation to the use of restraint by informal decision-makers. In the context of approved psychiatric centres, restraint is carefully overseen by specific provisions in the Mental Health Act 2001 and it would be wise to introduce a similar system in this legislation.

5. Circuit Court

5.1 The Bill outlines determination of capacity as a function of Circuit Court. There is, however, insufficient detail about how the Circuit Court will make this determination, and what its procedures will be. The decision-making required for this task is both difficult and subtle. Section 30 of the Bill outlines various reports that the Court may use but insufficient detail is provided in relation to the type of expert report required, the temporal relationship necessary between the expert's assessment and the Court hearing, or the number of reports required. Also, further detail is required in relation to procedures for arranging expert reports, and the number/type of reports allowed.

6. Legal Representation

6.1 The Bill makes insufficient provision for legal representation for the person about whom the application is being made. The Bill does specify that any party to the proceedings can retain legal representation at their own expense and there is also the possibility of legal aid. However, many elderly persons with dementia and many adults with intellectual disability about whom an application is being made may be unable to negotiate the issues in arranging their own legal representation or seeking legal aid.

6.2 By way of contrast, there is a well-developed system of automatic legal representation under the Mental Health Act 2001, and a similar system should be introduced as part of the new Bill. The College is similarly concerned that the Bill contains insufficient provisions for circumstances where an individual may wish to seek his or her own expert report. There seems to be no provision for procuring or paying for such a report in the Bill.



7. Office of the Public Guardian

- 7.1 The Bill specifies that the Office of the Public Guardian may prepare Codes of Practice. The College recommends that these Codes of Practice will give clear guidance on various matters (e.g. for health care professionals assessing capacity). To this end, a more detailed outline of the functions of the Office of the Public Guardian would be welcome. It is clear that Codes of Practice will be absolutely vital for the successful implementation of the final legislation. The College would welcome clarification on the development of the Codes of Practice and the proposed involvement of stakeholders in their formulation and review.
- 7.2 Under the new Bill, decision-making representatives and EPOAs will be subject to supervision of the Office of the Public Guardian and special visitors. This supervision will require them to abide by the guiding principles of the Bill. While the College welcomes this supervision, it is important to bear in mind that many of these individuals will be elderly relatives, already under significant strain caring for a relative with significant care needs. There will be a strong need for clear guidelines and education regarding the legislation and the resultant responsibilities for individuals assuming these assisted-decision making roles. Consideration should be given to support mechanisms for individuals who take on these roles, not least because, if these roles are too onerous, people may simply decline to engage in the process.
- 7.3 The College would also welcome greater clarification of the proposed sanctions for failure to comply with the legislation and its associated regulations or Codes of Practice (e.g. if co-decision makers and decision-making representatives fail to submit annual reports).

8. Areas Not Covered by the Bill

- 8.1 As mentioned above the exemptions from this legislation present complex dilemmas. Section 106 of the Bill lists a range of areas (e.g. marriage) which are not affected by the Bill and for which, therefore, existing laws are unchanged. The College reiterates the view that it would be most desirable if individuals who lack mental capacity could exercise legal capacity in *all* areas, including those areas exempted from this legislation (e.g. marriage).



On the other hand, the College understands the need to exclude certain areas from the assisted decision-making paradigms in the Bill; e.g. it does not seem reasonable that a decision-making representative should *ever* be able to decide that the individual he or she represents should get married. The potential for abuse in this situation is too great, and the College is aware of reports from other jurisdictions of individuals with significant disability being married in circumstances of dubious capacity and possible exploitation. In order to address these dilemmas further, the College recommends that existing laws relating to the areas excluded from this Bill be re-examined in order to identify ways in which those laws can be revised in order to accord greater legal capacity to individuals with impaired mental capacity.

- 8.2 The fact that pleading in court is not exempt may also create a dilemma. For example, if an individual lacks capacity to enter a plea in court, could that individual seek to appoint a decision-making representative to enter a plea on his or her behalf? The College feels that the Bill, as presently written, is insufficiently clear on this point.

9. Other Points

- 9.1 In the definition of lack of capacity (Section 3(2)), it is not clear how long an individual must retain relevant information in order to make a decision. The College suggests that point (b) incorporate part of point (c) so that point (b) reads “to retain that information for long enough to use or weigh that information as part of the process of making the decision”.
- 9.2 The College is concerned that the Bill does not specify that “undue pressure” should not be present when various decisions (e.g. appointing a decision-making assistant) are made. The College suggests that be introduced at appropriate points throughout the Bill in order to protect better the rights of individuals with impaired capacity.
- 9.3 The Bill is insufficiently clear on certain dilemmas which may arise in certain circumstances. For example, the Bill specifies that where a co-decision making agreement exists, any decision made without the co-decision maker is void. This may create practical difficulties, especially if the co-decision-maker and the person in question disagree.



- 9.4 The interface with the Fair Deal Nursing Home Support Scheme legislation needs to be clarified. Will it remain appropriate to use a Care Representative to apply for the loan in the case where the individual lacks capacity? This might mean two parallel systems in the Circuit Court for determining capacity in relation to financial affairs and two systems of appointing a representative.
- 9.5 This Bill states that “nothing in this Act shall be construed as authorising any person to give consent on behalf of a person who lacks capacity to be a participant in a clinical trial” (Section 103). The College is concerned that this may mean that a person with a severe intellectual disability could be prevented from potentially benefitting from, for example, a new cancer treatment. The College recommends that explicit measures to govern research be introduced, along the lines of those in Sections 30-34 of the Mental Capacity Act 2005 in England and Wales.

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